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## State Society and Governance in Melanesia

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## Report from the Field: HIV/AIDS in West Papua, July-Sept 2013

Jenny Munro

I recently spent about three months in West Papua, mainly in the central highlands town of Wamena, Papua province. Government statistics suggest an HIV prevalence in Papua province of 2.4 % of the adult population, but people working on HIV prevention and treatment based mainly in indigenous-operated non-governmental organizations (NGOs) state that 1 in 5 of the young indigenous men and women they bring to a clinic for testing turn out to be HIV positive. HIV in Papua follows ethnic lines, with 68% of infections occurring in indigenous Papuans. As of September 2013 there were about 3600 HIV/AIDS cases in Jayawijaya, the regency (*kabupaten*) in which Wamena is located, mainly occurring among indigenous people, who may number in total about 80,000. Because Wamena offers HIV testing and treatment, a result of targeted international donor and government efforts to create a flagship site in a remote part of West Papua, it is seen as a comparative success, a case of technological expansion and service delivery under trying geographic, cultural and political conditions. In this report I describe current conditions that test this view, as well as point to the obvious: Wamena can only seem good in comparison with the absolute lack of HIV services beyond the city limits and in neighbouring rural and remote districts.

Wamena provides testing and treatment for people from at least five different regencies (Puncak Jaya, Yalimo, Lanny Jaya, Tolikara, Jayawijaya), a territory of approximately 24650 km<sup>2</sup>, home to about 460,000 people. This is particularly daunting when you consider that much of the HIV testing and out-patient treatment is provided by about one hundred NGO staff (most of whom are outreach volunteers), ten NGO clinical staff, and a handful nurses and laboratory technicians at the public health clinic (*puskesmas*) in Wamena city.

For those needing the services, it is beyond daunting. I met a group of villagers coming in to Wamena from near the Puncak Jaya border. The taxi fare of 150000 IDR (about 13 AUD) per person was too much for the group of four, so they had walked part of the way

overnight to reduce the cost of the trip. They attempted to make the journey every month or two, and were often stranded in Wamena after their clinic visits, waiting for taxi fare home. Wim, one of the men, explained the impact of this dislocation: “Look at me, I am getting skinny again from working in my relatives’ garden. We can’t stay here and just sit idly for weeks, we have to work and hope that maybe later they [relatives] will give us money to get home to the village.”

Staff at the indigenous-run Klinik Kalvari estimated that among those many patients who do not live in Wamena, only 1 in 5 return to the clinic for treatment on an ongoing basis. In my conversations with patients, it was relatively common to hear that the person had started his or her diagnosis and treatment journey along with several relatives or friends, but was now alone in receiving clinical services. It is perhaps expected that the very new regencies, such as Lanny Jaya or Yalimo, do not have the services, but Puncak Jaya is the second oldest regency in the central highlands, with the town of Mulia serving as capital city, at least on paper, since 1996. It is also the regency most plagued by violence and human rights abuses, perhaps contributing to the 2012 departure of the only HIV service provider, *Medicins Du Monde*.

### **The traditional volunteers program**

Besides the location of services, uptake of testing and acceptance of treatment routines has been challenging. Indigenous-led NGOs are at the forefront of responding to these challenges. In 2011, local group Yukemdi joined forces with Australia-funded HIV Cooperation Program for Indonesia to shape a new effort at outreach for promoting awareness and HIV testing: the ‘Traditional Volunteers’ (Relawan Adat) programme was debated and discussed at two roundtable forums in Wamena with the local traditional council (DAP Baliem) and members of the public before it went into action. As of August 2013 the programme was funding over 100 indigenous staff working largely as mentors in their own neighborhoods and villages.

The volunteers take what Yukemdi director Yoram Yogobi calls the 'socio-cultural' approach. They inform people about HIV transmission, prevention and testing in whatever informal or formal opportunities they come across – on the street, on a bus ride, at a funeral, at church, making use of high levels of social interaction typical in Wamena (and Papua) to share HIV information. A key bit of local wisdom is that hardly anyone will agree to HIV testing the first time they speak to an outreach volunteer. So, multiple interactions over time are necessary. A relationship develops. A volunteer becomes known in their neighbourhood as a person who can facilitate HIV testing, and perhaps other needs for clinical service.

Among the advantages of having locals do this outreach is that they may use their local language or a mix of languages to improve clarity and to connect with people. The volunteers also make themselves available to take people to the VCT clinic if they wish to get tested, and often become known in the neighbourhood as someone who can facilitate access to these and other health services. They usually wait at the clinic with the individual getting tested, and may even enter to hear the test results together if the person agrees.

Ideally, this is the start of a relationship, whether the individual tests positive or negative. If a person tests positive, the volunteer will keep in touch with them and come back to the clinic with them each time they are required to see the nurse or doctor, collect medication or undergo blood tests. Having this relationship typically means that volunteers are there to explain what an HIV positive result means, to respond to questions about the social and political aspects of HIV, to explain how to manage the condition, and to provide advice and comfort to those who experience panic and fear at the result. Sometimes volunteers hang around the VCT site keeping an eye out for confused or lost people who are trying to figure out how to access HIV testing, or those who are too unwell to manage the clinical encounter on their own.

The logistics of getting people to testing and treatment are also challenging in Papua. In Wamena, a ubiquity of mobile phones helps with this effort, but there is no more valuable

tool for HIV treatment than a dedicated volunteer with a motorbike to enable checking up on mobile clients and giving them a ride to the clinic. These programmes engage the best of highlands sociality and new forms of mobility by turning a one-off clinic encounter into potentially a longer term interaction that may extend to forms of care and giving, or to deeper discussions about HIV and sexual health.

Unfortunately, an effective mentorship programme requires a large number of volunteers to provide the appropriate coverage and to overcome obstacles of communication and geography in and around Wamena. Volunteers normally receive an honorarium of 500,000 IDR (about 50 AUD) per month, but ought to be paid more to reflect the important role they are performing. This honorarium is far below a living wage, which means that volunteers may feel compelled to leave the NGO for other employment.

### **Principles of respect and cultural engagement**

The indigenous-run Klinik Kalvari is also demonstrating ways to connect with patients and to improve patients' understanding of HIV treatment. Staff recently produced a "fence model" that they use to explain HIV to new positive clients, or other clients who have missed follow-up visits and treatment. The model is designed as miniature traditional *silimo* (extended family residence) with a number of huts (*hona*) surrounded by a protective fence. The fence, clients are told, represents a person's CD4, or immune system cells. HIV creates perforates the fence, by which pigs (opportunistic infections, and well-known to indigenous locals as destroyers of cultivated gardens) can enter the *silimo*/body. Taking antibiotics first is meant to shoo the pigs out of the yard, then antiretroviral medication (ARV) helps rebuild the fence. Staying on medication helps keep the fence (immune system cells) solid and intact.

The development and use of this 'fence model' speaks to a broader goal that is embodied in the clinic's services: to serve patients in a way that respects and engages local social, cultural and linguistic norms. The norm at the clinic is for patients to be greeted with a

handshake by the front desk nurse who asks how they are doing before taking blood pressure and measuring body weight. The clinic is proud to offer services in all of the main local languages (and dialects), and indeed does receive many out of town clients who prefer their mother tongue to Indonesian.

### **Challenges to local expertise**

Perhaps the ‘take-home’ message I received from Wamena during my time there was that local knowledge, local experience, and local networks are what is enabling HIV services to run in Wamena with any measure of success. Yet international donors (and their national Indonesian branches and partners) who are funding and setting priorities for HIV services, take actions that are counter to this strength by bringing in ‘experts’ from Jakarta to run research and other studies, for example, or by continually replacing and relocating staff just as they begin to function well in the highlands. Beyond whatever internal logic there is to these types of decisions, it is the kind of approach that dismisses and dismantles what could be an essential component of a locally-defined effort to overcome the epidemic.

Another scenario: I was told a story about a group of international donors, led by the Global Fund, who, in response to criticisms that there have been no condoms available in Wamena for the past eight months, propose a study to use GPS (Global Positioning System) technology to map out condom availability. Markus, an informant at Klinik Kalvari states, in exasperation, “First, we tell them, there are no condoms to map out. Then, we say, if the KPA would spend money to fly in the condoms like they are supposed to do, then, everyone here knows where you can get condoms, we don’t need a GPS for that.”

Success, in local views, is that over 3000 people in Jayawijaya regency have had their HIV detected. Some are either being treated at Kalvari or being coordinated to the public health clinic by volunteers. The reality is that services can barely keep up with the proportion of those 3000 people who do attend treatment services. Tius, a Kalvari staff member pointed out, “Even if everyone did come back, we could not take care of them.” At

regular meetings, Yukemdi staff share stories about clients (sometimes they call them friends or relatives) who are doing okay, and those who have lost their battle. This style of debriefing is part of making HIV services less about numbers and targets and more about human beings. Yukemdi, unlike most other NGOs in West Papua, does not set VCT or outreach targets. These local NGOs are proud of their ability to save lives by connecting people with treatment, and it forms part of their upfront dialogue with clients, and internally. They mobilize potent expressions of indigeneity and Christianity, promoting the logic of 'saving our people' as a way of connecting with the public, policy makers and key officials, as well as clients and volunteers. The reassurance that medicine can put right all that has gone wrong in a person's body, and, perhaps their life, is a powerful claim that may keep HIV positive persons coming back, despite a potentially arduous social and geographic journey.

### **Bad news, good news**

Local NGOs workers are tired of hearing, and bearing, the bad news about HIV in Wamena. But other commentators are overly optimistic about treatment success in the highlands, and beyond. Indonesia is one of a handful of countries in the Asia-Pacific where HIV infection rates continue to rise. To say that testing and treatment is functioning for some people (only) in Wamena is not to say that people living with HIV are generally being cared for and embraced by their relatives or the wider community. I met a young woman who lived across the street from a Yukemdi staff member from the same clan, and yet, she described ostracism from her sister and brother-in-law with whom she was staying: "Sometimes I just stay in my room alone, hungry and crying." Another young woman was blamed for her boyfriend's headaches and fainting spells. One day, he collapsed and his mother and sister beat Julia with a frying pan and other kitchen implements.

Confidentiality in the VCT clinic is getting a higher degree of attention but peoples' secrets are not necessarily safe. Confidentiality, while a key principal in international models



of HIV testing, produces an enormous challenge for highlanders, because secrets imply that people have something to be ashamed of, and because silence around an HIV diagnosis makes it easy to disconnect and disappear. Where NGOs in other parts of Papua are banned from entering the VCT room with a client in fear of confidentiality breaches, I have seen that one trustworthy confidante can save a life by keeping an HIV positive person connected to treatment. There are no easy answer to the problem of confidentiality, but there is certainly room for more open and less judgmental dialogue about the ways it really works, and doesn't work, locally.

The good news is that there are innovations in ways of engaging people and spreading the word about HIV through conversations that build on local strengths of social interaction, on the ways that people are very good at establishing rapport, and connecting over betelnut or coffee, at funerals, on the bus, in the market place, at the ATM machine in the city centre. There are innovations in ways of doing VCT such that testing initiates and relies on social bonds, via the use of volunteers who provide continuity with what many feel is still a daunting clinical/bureaucratic encounter. Solidarity around HIV as 'our' problem, not the problem of MARG or MSM or PSK, is growing in spite of programmes and policies that perpetuate false categories of risk, and an infinite number of ways of dividing people up.

Unfortunately, donors with money to spend on HIV in Papua are often not interested or not able to find ways to work productively with these NGO-led activities. For example, after an experience with USAID where 40000 USD was promised to Klinik Kalvari to help build capacity for nurses and doctors wishing to work in Papua, Kalvari is no longer really interested in big donors. Almost all of the funding was spent on the participants involved in the training, mainly hotels, flights, and packed lunches (nasi bungkus), while Kalvari was unable to operate its usual services for clients as the place was overrun with trainees. Despite the essential role they play in the central highlands, Kalvari at times does not have funds to pay its staff. They operate without an HIV specialist doctor, partly because a doctor costs more than 10 highly qualified and dedicated nurses. Yukemdi attempts to work with

donors but suffers dearly when programs are continually suspended, delayed, cut, or reorganized. They lost many of their most experienced staff when USAID postponed their SUM II program for 8 months in 2012, leaving the staff with no wages.

### **The role of the AIDS commissions**

With the support of local allies in the NGO community, I would like to signal an overlooked but important aspect of the inadequate response to HIV in the highlands, and beyond: government policy and practices, including the provincial and local AIDS commissions (*Komisi Penanggulangan AIDS* or KPA), which receive international donor funds. For example, in Wamena, the local KPA was provided with an expensive new Toyota Hilux pick-up truck to be used to take HIV messaging around Jayawijaya, literally. Even districts near the capital city may not have electricity, making audio visual presentations difficult, and the truck is supposed to be used to carry a generator where needed, as well as expensive electronic equipment that would otherwise be transported over bumpy roads in a motorcyclist's backpack. Locals allege that the vehicle is almost always being used as the private vehicle of the KPA secretary.

This scenario reflects a widespread pattern. In a coastal town in West Papua province, the local KPA took its 12 members to Makassar to study their HIV services. Upon returning from Makassar, the KPA secretary confessed to me that they never set foot inside a hospital, health clinic, laboratory, or Voluntary Testing and Counseling (VCT) centre. He commented, "We did not learn anything in Makassar, except that their situation is very different from ours." In Indonesia, people are very familiar with the practice of 'comparison study' (*studi banding*) as a means of financing an enjoyable excursion that is considered a legitimate use of government funds. Meanwhile, an HIV NGO in the same city scrambled to come up with 500 USD to send an HIV positive woman to the provincial capital to give birth by caesarian section and reduce chances of HIV transmission to the baby.

Frustration with government, particularly the local level AIDS commissions, is extremely high among local Papuan NGO HIV service providers. For example, Yukemdi and Klinik Kalvari, among others, have been advocating the need to develop HIV services in diverse and distant areas. Recently, the KPA and other government agencies echoed this need. However, rather than a sense of relief or success at this announcement, indigenous NGO workers in Wamena expressed concern that government intervention may thwart rather than advance the cause of remote services, because in their experience government intervention brings a massive amount of disorganization, bureaucratic red tape, and wasted resources.

Dealing with dysfunctional KPAs who are often acting in violation of their mandate because they want to directly implement activities (where the money is) rather than provide leadership, amplifies the stress experienced by service providers who are taxed with the enormity of the epidemic, as well as the morbidity and mortality of their friends, relatives, and neighbours.

### **Policy impacts on HIV**

Broader political conditions, including fear of security sector violence and norms of repressing civil liberties, work against public critique of HIV services. Without critique, inefficiencies and corruptions may continue unabated. The ongoing segmentation of the region into more regencies and districts (*pemekaran*) is also creating barriers to HIV services, as well as making it difficult to monitor the epidemic. There simply are no HIV services outside of Wamena, but *pemekaran* creates a smokescreen that shields us from this reality. The priorities for new administrative zones are infrastructure and human resources, not HIV services. Moreover, HIV risk is created when a new regency or district crops up, bringing construction projects, labour migration, and an influx of cash, but no corresponding public health response. Local wisdom suggests that the more money flows into Wamena, the more HIV circulates too. It is hard to look away from the human suffering

and devastation, largely undocumented, that HIV is creating in the highlands. However, it can be productive to take local wisdom seriously, and to ask hard questions about current conditions. It is a sad state of affairs when the local government agencies charged with providing leadership and guidance for the HIV response are embroiled in corruption, and lack both the ideas and the authority to provide genuine leadership.

### **Reality check**

These recent experiences have led me to an odd line of questioning: Are HIV programs and services that seem expensive, non-standardised, and hard to monitor, necessarily problematic if they are effective? As attention to HIV in West Papua grows, and money floods in, I support local allies who are advocating for an approach that pays attention to their innovations and strengths, even if it is a matter of taking more time in the process to have better results in the end. Programs that put short term project cycle goals ahead of principles of sustainability and collaboration are not only a waste of money, for they may achieve very little, but devalue the very people and practices that are essential to leading this fight. It is useful to examine how our responses to the epidemic exacerbate or, hopefully, decenter, conditions of exclusion, and inequality. Fortunately, or unfortunately, major international donors and local government agencies are also speaking the language of community leadership and empowerment. It remains to be seen whether these agendas translate into a power shift in how HIV responses are produced and enacted, or whether leveraging local participation simply means cost sharing, or otherwise pressuring Papuan NGOs to fit into limiting models of pre-established program and policy wisdom.

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